

## MEMORANDUM

DATE: May 31, 2007

TO: All Members of the Delaware State Senate  
and House of Representatives

FROM: Ms. Daniese McMullin-Powell  
Chairperson  
State Council for Persons with Disabilities

RE: S.B. 78 [PKU Insurance Coverage]

The State Council for Persons with Disabilities (SCPD) has reviewed S.B. 78 which provides that certain medical formulas and food expenses in the on-going treatment of Phenylketonuria (PKU) and other inherited metabolic diseases shall be covered in health insurance contracts and also in group and blanket health insurance policies. As background, please see attached background materials. Phenylketonuria (PKU) is a hereditary disease caused by lack of a liver enzyme required to digest phenylalanine, an amino acid in many protein-containing foods. The gene defect is a recessive gene trait. Ninety percent of affected persons have blond hair and blue eyes. Incidence is approximately 1 in 17,000 live births. PKU-affected children who are not placed on a special diet suffer irreversible brain damage and mental retardation. According to the attached table authored by the National PKU News, approximately thirty (30) states require private insurers to cover PKU-related foods/formula. Of the thirty (30) states, most also require coverage of food/formula for other inherited metabolic diseases as well. Delaware's neighboring states adopted legislation requiring such insurance coverage more than a decade ago [Maryland (1995); Pennsylvania (1996); and New Jersey (1997)]. S.B. 78 is based on the Maryland law which is touted as a model by the PKU News. It was included in the Insurance Commissioner's Legislative Agenda released on March 19, 2007.

SCPD endorses this important disability prevention bill with one caveat, i.e., the sponsors may wish to consider whether the bill should be strengthened. The bill literally requires insurers to "cover" food and formula. In theory, an insurer could create a separate category of "coverage" of metabolic disease-related food/formula with high co-pays or deductibles. The insurer could essentially pay "lip service" to the law by providing very limited "coverage" through a meager subsidy of costs. Contrast the mental health parity statute [Title 18 Del.C. §3577(b)] which is prescriptive in

addressing insurer coverage standards. The sponsors may wish to consider options in this context.

Thank you for your consideration and please contact SCPD if you have any questions regarding our position or observations on the proposed legislation.

cc:     The Honorable Ruth Ann Minner  
          The Honorable Matthew Denn  
          Governor's Advisory Council for Exceptional Citizens  
          Developmental Disabilities Council

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